

NOTICE OF PUBLIC HEARING
ON NEWBORN METABOLIC SCREENING RULES
DEPARTMENT OF HEALTH
STATE OF HAWAII
DOCKET NO. R-7-03

Pursuant to sections 91-3 and 92-41, Hawaii Revised Statutes (HRS), notice is hereby given that Department of Health will receive written comments and hold a public hearing concerning proposed changes to Hawaii Administrative Rules (HAR), Chapter 11-143, "Testing of Newborn Infants for Metabolic and Other Diseases."

The subjects and purposes of the proposed changes will include the following:

1. Add, delete, and clarify terms, including: "amino acid disorders", "fatty acid oxidation disorders", "organic acid disorders", and "urea cycle disorders".
2. Add the diseases that will be screened in the expanded newborn screening testing panel, effective September 1, 2003. The additional disorders which will be screened include amino acid disorders, fatty acid oxidation disorders, organic acid disorders, and urea cycle disorders.
3. Change the fees from \$27 to \$47 for each newborn screening kit, effective September 1, 2003. The fees will be deposited into the newborn metabolic screening special fund, which will pay for costs, including the centralized laboratory testing of over 25 disorders; repeat tests; confirmatory tests; specimen collection and handling; specimen courier costs; contracted nutritionist, pediatric endocrinologist, and metabolic specialist services; state administrative overhead; staff salaries and fringe benefits; and newborn screening program services (follow-up, tracking, professional/community education, educational materials, assessment, assurance, system/policy development, newborn screening for the indigent, etc.)
4. Delete the requirement for hospital charges for newborn screening to be reported to the department annually, because the charges for newborn screening are part of the global fee for delivery and care of the newborns.
5. Allow other persons having custody or control of the child the right to be informed of the need for initial, repeat or confirmatory testing, and the right to refuse the screening tests

if the tests conflict with their religious tenets and beliefs. This change conforms to the wording in HRS§321-291.

6. Delete the requirement of the designated newborn screening testing laboratory to report monthly and annually the number of confirmatory tests by disorder and the number of confirmed cases by disorder. This data is more easily available through the newborn metabolic screening program than the testing laboratory.

Persons desiring to speak are asked to submit two copies of their testimony before or at the hearing. Written testimony will also be accepted until 4:30 p.m. on September 30, 2003 at the Newborn Metabolic Screening Program, Children with Special Health Needs Branch, 741 Sunset Avenue, Honolulu, Hawaii 96816.

The Public Hearing will be held on September 29, 2003 at 1:00 p.m. at the following Video Conference Centers:

Keoni Ana Building, 1177 Alakea Street, Room 302, Honolulu, Hawaii

Hilo State Office Building, 75 Aupuni Street, Basement, Hilo, Hawaii

Wailuku Judiciary Building, 2145 Main Street First Floor, Wailuku, Maui

Lihue State Office Building, 3060 Eiwa Street, Basement, Lihue, Kauai

Copies of the proposed rules and documents explaining the proposed changes are available at the follow locations:

Oahu Newborn Metabolic Screening Program, 741 Sunset Avenue, Honolulu,
Hawaii

Hilo District Health Office, 75 Aupuni Street, Hilo, Hawaii

Maui District Health Office, 54 High Street, Wailuku, Hawaii

Kauai District Health Office, 3040 Umi Street, Lihue, Hawaii

The proposed rules will also be mailed or faxed at no cost upon request or available via http://www.state.hi.us/doh/proposed_rules/nbms. To obtain the proposed changes to HAR Chapter 11-143, call the Newborn Metabolic Screening Program at (808) 733-9069 or write to Newborn Metabolic Screening Program, 741 Sunset Avenue, Honolulu, Hawaii 96816.

Any person having special needs due to disability, please contact the Newborn Metabolic Screening Program at (808) 733-9069 or Voice/TTY at (808) 733-9055 by September 8, 2003.